



**Friday, July 31, 2015  
Breakout Session #23: 3:30 - 4:30pm  
Schaumburg E-F**

**Quality Not Quantity – Thoughts on  
Communication, Behaviour, Play and  
Passions**

**Rob Last  
CHARGE Syndrome Association of Australia  
and New Zealand**

**Presenter Information:**

Rob Last is a special education teacher who has a long history working with children who have sensory disabilities, particularly in hearing and vision. Since the mid 1980's he has been involved with children who have CHARGE syndrome and their families. He and a group of parents established the CHARGE Syndrome Association for Australia and New Zealand in the late 1980's. Rob has been a presenter at many of the CHARGE Syndrome International Conferences since the first in St Louis in 1993 and the first CHARGE Syndrome Conference in Australia and New Zealand held in Sydney 1994. He presented at the CHARGE Syndrome Conference in Germany in 2012. Rob's career has been as an Early Childhood Educator with the Royal Institute for Deaf and Blind Children in Sydney and the Royal Victorian Institute for the Blind and Vision Australia in Melbourne, Australia.

He continues his work with the CHARGE Syndrome Association of Australia and New Zealand as a Director for the state of Victoria and as Director of Outreach for Australia and New Zealand. Rob has the pleasure of meeting and being in contact with families from all over Australia and New Zealand as well as the CHARGE international community.

**Presentation Abstract:**

The presentation will focus on early communication and behaviour, address the importance of establishing a meaningful communication system for children with CHARGE and the strategies that may be available for this. Play strategies will be demonstrated through video, photos and discussion. Passions/obsessions as educational opportunities will be discussed and illustrated through video and photos. We will discuss the importance of appropriate early intervention strategies to ensure positive outcomes. Case studies and photos will support this discussion. 'Meltdowns' will be discussed as a form of communication, why these may occur and strategies for managing these. Communication systems will be highlighted as well as the supports available in the acquisition these.

## **HANDOUT FOR ATTENDEES**

**12<sup>th</sup> International CHARGE Syndrome Conference  
Chicago, USA, 30 July – August 2, 2015**

**Quality not Quantity  
Thoughts on:  
Communication, Behaviour, Play and Passions**

### **Rob Last**

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### **Introduction**

Conferences are filled with highly experienced experts, these being parents and professionals and those who have CHARGE.

So I hope to offer some new and old thoughts on communication, behaviour, play and passions.

My primary focus throughout my career has been communication; communication with babies, children, teenagers and adults.

I believe it is one of the keys to breaking through, to find the person.

I also mean all kinds of communication, simple to complex and in it's many forms.

### **Nikki**

Not long ago I participated in a Skype meeting with a family I hadn't met. It was a really useful meeting as I realised many of the things I've been saying for years are still relevant.

I met Megan; mother of Nikki, who at this time was 3 and 1/2 years old and some members of her cochlear implant team, Niiki had received a cochlear implant about 18 months previously.

The meeting was to discuss the impact of CHARGE syndrome on Nikki's development.

The all too familiar CHARGE scenario was described, multiple hospitalizations, surgeries, a range of interventions, all completely overwhelming for Nikki and her family.

More recently things were just starting to settle down with less hospitalisations and illnesses.

Nikki was described as having been withdrawn and anxious and was now 'emerging from her withdrawn behaviour' with everyone around her being very excited by the changes.

As we know many things may happen to children with CHARGE without warning or preparation.

Educators familiar with children with dual sensory impairment strive to educate the medical and therapy teams in strategies to alert the child as to what is about to happen. They often do this verbally ('I'm going to give you an injection now') but don't add in touch cues, gestures, pictures, drawings, anything that will help prepare the child for what is about to happen.

Nikki needed to understand what was going on around her, what was happening to her, what was going to happen, would it be painful, Nikki needed information meaningful to her to ease the stress of her already chaotic and confusing life.

Nikki was described as being 'anxious' and I was asked is anxiety typical in children with CHARGE.

'Anxious' is a word I hadn't often used before to describe behaviour in children with CHARGE.

I was surprised I hadn't used it more in this context.

Yes of course children, teenagers, adults with CHARGE are anxious.

Why would they be anxious?

They need to know:

- what is about to happen
- when will it happen
- that it needs to happen now
- then what is going to happen after that
- and after that, after that ...

Other terms are also used such as:

- obsessive compulsive disorder (OCD)
- autism spectrum disorder (ASD)
- repetitive behaviours
- attention deficit disorder

- tics
- self-harm
- non-compliance
- tantrums
- meltdowns.

We often talk about how all the behaviours we see in children with CHARGE are perhaps exhibited by everyone; it's just that people with CHARGE really amplify these behaviours.

I remember in one of Tim's presentations a few years ago he had a slide of the things that define Obsessive Compulsive Disorder.

I must tell you I scored really well on that OCD screening test.

Order, organisation and tidiness have a really important purpose for me. It keeps my world orderly, predictable and easy to access.

I think those words predictable, orderly and easy to access apply to many of those with CHARGE.

### **Meltdowns**

We talk about Meltdowns a lot.

It seems to me that one of the contributing elements would be anxiety.

In the early years

- What are you doing to me?
- What are you going to do to me?
- I don't understand what's happening
- That hurt
- I feel sick

In the later years

- I want it now
- I want it to happen now
- You are not listening to me
- You do not understand what it is I want

- You didn't understand what I meant
- You just didn't understand
- You haven't explained it to me and I'm unsure as to what is happening or what is expected of me
- Will it happen now?
- What will happen next?
- What will happen after that ... then after that?

These anxieties may lead to

- Distrust
- Fear
- Anxiety
- Outbursts
- Refusal
- Withdrawal

At that Skype meeting I explained how 'Meltdowns' are not restricted to age or development. I've seen 'meltdowns' in babies, children, teenagers and adults. From those with high support needs to those who are independent, mainstream educated and employed ... the whole spectrum.

What I've observed over the years is that nearly all of those who have CHARGE have functional vision. They may be legally blind but function extremely well visually.

I've always felt we must use all senses as a means of providing meaningful information, even though we know all senses are affected.

Therefore using visual language and touch cues to support spoken language is of great importance to me.

So for parents, educators, therapists and doctors it's our challenge to make every effort to make their world more predictable, more ordered, more organised and tidier, using all possible means to achieve this.

- what will happen now
- what will happen next
- what will happen after that
- then after that and so on

to reduce distrust, fear and anxiety.

I digress, back to Communication

At that Skype meeting I reiterated my belief that it's our job is to help make sense of this chaotic, unpredictable world for the baby, child, teenager and adult.

In talking to Megan (Nikki's Mum) about communication we discussed communication as a complete entity.

I often hear the focus being speech as communication and secondly sign language. Speech is of course the most desirable as it's the mother tongue of the home and the world. The aim of speech being the most desirable outcome is an appropriate aim.

Parents and professionals always strive to provide the best possible audition through: amplification, hearing aids, cochlear implants, bone aids, bone anchored hearing aids, FM systems.

I also maintain we need to add all types of 'visual language': sign language, key word signing, gestures, body language, facial expression, pointing, mime, real objects, symbolic objects, photos, drawings, symbolic drawings (boardmaker, proloquo2go) and reading and writing.

Multimodal communication.

### **About Learning Sign Language**

I acknowledge that acquiring a new language like American Sign Language (ASL) is a big challenge.

Here are a few suggestions to assist in this process.

- use teachers of the deaf fluent in sign language
- use signing dictionaries
- use DVD's teaching sign language
- seek out members of the deaf community
- seek out CODA's (Children Of Deaf Adults)
- attend classes/courses
- attend events with the deaf community
- find a neighbour, friend of a friend, someone who is fluent in sign language
- choose voice off times to rely on signs language only

## **Play with Younger Kids**

Of course play is also communication.

Parents report that bonding and attachment is severely interrupted when they have a child with CHARGE. One of the challenges is building a trusting relationship through offering interactions and communication that are meaningful, that will make sense, that will be understood, that will be fun, that will be interesting and will be rewarding and worthwhile.

Nikki is only just embarking on this journey.

Her parents and therapy team have progressed gently and cautiously. This has come from an understanding as to why her early experiences have caused her to withdraw into that inner place, that place where she feels safe.

The adults have engaged in careful and gentle encouragement to enable Nikki to trust and engage in the world outside her body.

They began by joining Nikki in her world.

## **Heiko and Jonas**

In this presentation I show three movie clips of a Dad, Heiko, and his son, Jonas, The movies shows them engaged in relaxed and pleasurable play.

Heiko uses simple strategies to engage Jonas in play.

The movie is in German so it is interesting to notice how much is understood without understanding spoken German, how much the visual communication explains what is going on.

(Movies – Heiko and Jonas)

So what was noticed about play in the movies.

### **Movie 1**

- Heiko gains Jonas's attention
- He prompts turn taking
- He rewards imitation
- He pauses while Jonas looks at the camera.
- Rewards again with 'Bravo' and 'clap, clap'
- He allows looking away
- He uses speech, gesture, signs and more
- It was also interesting and fun

## Movie 2

- Jonas is well supported on his dad's body
- Dad is also comfortable
- Dad follows Jonas's interests
- Allows time for Jonas to process information
- Responds to Jonas's request for a repeat
- Dad uses animated, interesting and rewarding facial expressions

## Movie 3

- This one depicts more adult directed play
- Heiko takes his time to ensure Jonas understands the game
- He revises the steps to ensure Jonas has every chance to succeed
- He allows Jonas to succeed without adult intervention
- Success is Jonas's reward

## Heiko used

- Speech
- Sign language
- Facial expression
- Singing
- Body language
- Gestures
- Mime
- Touch cues
- Symbolic objects
- Real objects
- Photos
- Drawings

## To engage in successful play the adult must

- Follow the child's lead
- Capitalize on interests
- Provide interesting choices
- Break tasks into achievable steps
- Provide developmentally appropriate tasks
- Encourage and support self-discovery
- Provide meaningful communication



- Plan for success
- Experiential learning is often the best learning

And it's a good idea for the adult to rediscover their inner child

### **PLAY - Play is Children's Work**

A parent reminded me to mention that often professionals engage in play without explaining what it is they are trying to achieve and what they are looking for.

Teachers and therapists understand that play is children's work and know that through play an assessment of abilities can be achieved. They note gaps in abilities and use play to teach to those gaps.

In the early years it is following the interests of the child in play which progresses into adult/teacher directed play in the later years.

It should always be:

- Stimulating
- Rewarding
- Challenging
- Meaningful
- Enriching
- Experiential
- Fun

### **Play for Older Kids**

#### **Passions/Obsessions**

We all have them. We are much more content when we are able to engage in our passions/obsessions.

Using passions/obsessions to support learning is good teaching.

These may be through

- Sean and Bailey – Lifts
- Trent - Technology
- David – Horse riding
- Sarah – Horse riding
- Phillip - Tapestries
- Belinda - Travel
- Ellen – Facebook
- Sean – Caravans

- Julia – Sorting and Organising
- Mitchell – Football and Spinning
- Sophie – Basketball

Use these behaviours to:

- Educate – for example; language building, reading, writing, maths, science, geography, social skills, self-help skills, organisational skills, planning skills and more
- To establish and develop friendships
- As a hobby
- For pleasure
- To provide relaxation
- To enhance self esteem
- As exercise
- To further encourage communication
- As a possible career plan

AND

- Focus on the passion
- Plan ways of engaging with the passion
- Involve friends in the passion
- Find others with the same passion
- Record through photos, filming and writing
- Have fun
- Remember experiential learning is the most powerful.

### **Take Home Messages**

- Communication means auditory and visual expressive and receptive language
- Be thoughtful and thorough in preparing for routines and events
- Use play for learning and social outcomes
- Use passions/obsessions for learning and social connections ... and maybe a career opportunity

## **Reading tips**

### **Four Great Books**

- 'An Exceptional Fellow' A Father's Story - Svein Olav Kolset  
To purchase: <http://anexceptionalfellow.com/>
- 'Far From The Tree' - Andrew Solomon  
Available from Amazon and The Book Depository
- 'CHARGE Syndrome' - Hartshorne, Hefner, Davenport, Thelin  
Available from Amazon
- 'Why I Am Me' - Ward, Patterson and Levett  
Purchase at this conference or from Australian/NZ CHARGE website:  
<http://www.chargesyndrome.org.au>

### **Families as Resources**

- Parents, siblings and grandparents
- Each and everyone here is a resource
- Find out who has similar issues
- Access each other via email, phone, social media, face-to-face
- Be a pro-active resource to others
- Notice with whom you feel a connection
- Swap contact details
- Use each other as needed

### **Other Human Resources**

- All the speakers
- All the parents and grandparents
- All those who have CHARGE syndrome

**Thank you**

**Rob Last**